Department of Health and Human Services National Institute of Environmental Health Sciences National Cancer Institute

Minutes of the Research Translation, Dissemination, and Policy Implications Subcommittee of the Interagency Breast Cancer and Environmental Research Coordinating Committee

December 13, 2011

The Research Translation, Dissemination, and Policy Implications (RTDPI) Subcommittee of the Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) was convened for a meeting on December 13, 2011 at 3:00 PM EST via conference call. The Chair of the subcommittee was Jeanne Rizzo, R.N. of the Breast Cancer Fund.

Subcommittee Members Present

Beverly Canin Ysabel Duron Ronda Henry-Tillman, M.D. Karen Miller Marcus Plescia, M.D., M.P.H. Jeanne Rizzo, R.N. Shelia Zahm, Sc.D.

NIH Staff Present

Jennifer Collins, M.R. (NIEHS) Christie Kaefer, M.B.A., R.D. (NCI)

Guests

Kathy Brown-Haumani, M.S. (The Scientific Consulting Group, Inc.) Connie Engel, Ph.D. (Breast Cancer Fund)

I. BACKGROUND

The Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) is a congressionally mandated body established by the National Institute of Environmental Health Sciences (NIEHS), in collaboration with the National Cancer Institute (NCI). This Committee is comprised of 19 voting members, including representatives of Federal

agencies; non-federal scientists, physicians, and other health professionals from clinical, basic, and public health sciences; and advocates for individuals with breast cancer.

The Committee's primary mission is to facilitate the efficient and effective exchange of information on breast cancer research activities among the member agencies, and to advise the NIH and other Federal agencies in the solicitation of proposals for collaborative, multidisciplinary research, including proposals to further evaluate environmental and genomic factors that may be related to the etiology of breast cancer. The Committee serves as a forum and assists in increasing public understanding of the member agencies' activities, programs, policies, and research, and in bringing important matters of interest forward for discussion.

The objectives of the RTDPI Subcommittee of the IBCERCC are integrated and dependent on the objectives and activities of the other Subcommittees of the IBCERCC and include the following: to identify successful models as well as gaps in research translation and dissemination, to make recommendations to improve both with an emphasis on breast cancer and the environment; to make policy recommendations to that end; to address areas in which the scientific evidence on breast cancer and the environment supports precautionary public health policy; and to identify methods to expand public participation in the research translation and dissemination processes to more effectively involve patient advocacy and community organizations, environmental health, environmental justice as well as practitioners in public health and health care delivery.

The ninth meeting (conference call) of the RTDPI Subcommittee took place on December 13, 2011. During this meeting, the Institute of Medicine's report, *Breast Cancer and the Environment: A Life Course Approach*, was discussed, along with the progress on the IBCERCC's draft chapters.

II. DISCUSSION

Institute of Medicine Report

The RTDPI Subcommittee members briefly reviewed the list of potential items from the Institute of Medicine (IOM) report, *Breast Cancer and the Environment: A Life Course Approach*, that might be appropriate to review and discuss in the RTDPI sections of the IBCERCC report.

The Subcommittee members felt that the IOM summary and Q&A documents differed a bit from the full report in terms of the key issues raised; however, these are the documents that the media looked at. The IBCERCC needs to ensure that its Executive Summary really captures the most important points of the IBCERCC report. Additionally, Beverly Canin said the IOM report presentation at the San Antonio Breast Cancer Symposium didn't reflect the substance of the IOM report.

In terms of similarities and differences between the IOM report and the draft IBCERCC report, Jeanne Rizzo said the IOM report contained a lot of content in its narrative regarding the importance of animal testing and radiation, but it used weak language in terms of what should happen or what people should do. It is also unclear whether "weight of the evidence" was considered, and it was difficult to find any references to "precaution," and some other words that are important to the IBCERCC, such as "translation" and "advocate."

Shelia Zahm felt that the IOM's charge was very narrow and the IBCERCC's charge is much broader. In terms of regulation, the IOM report referred to a 2009 GAO report calling for better Federal oversight of chemicals; however neither the 2008-2009 President's Cancer Panel report on environmental factors in cancer or the National Conversation on Public Health and Chemicals was cited in the IOM report.

The IOM report does contain a very brief discussion of communication issues (about two pages). There is some limited discussion of translation on page 3 of the IOM report. Jeanne thought there was less in the IOM report for RTDPI members than for the rest of the IBCERCC members; however, the RTDPI Subcommittee may want to add some text to the IBCERCC report about communication regarding life-course exposures, biologically plausible risk factors, and radiation.

IBCERCC Report

Other Subcommittee Chapters

Jeanne Rizzo sent a copy of the combined IBCERCC report chapters (version 4 from Kathy Brown-Haumani) for the RTDPI Subcommittee to review. The purpose of the review is not to edit the other Subcommittees' work; Kathy from SCG will do all the editing that is needed. The goal is to identify any questions RTDPI members may have about the content generated by the State-of-the-Science (SOS) and Research Process (RP) Subcommittees and look for ideas that should be incorporated into the RTDPI sections. When providing feedback, RTDPI members were asked to cite specific pages unless an overall point is being made.

Ysabel Duron did not think the SOS sections have compared and contrasted risk factors for women of color and what is known about individual impacts on under-researched populations. Jeanne also stated that environmental justice research issues have not been addressed, such as high exposures in certain sub-populations based on occupation. This information needs to be communicated back to the SOS Subcommittee. There was also uncertainty whether the RP Subcommittee would address these issues. Jennifer Collins agreed to email the RP members to ask their thoughts on the topic. Jennifer recommended that first research gaps should be identified in the SOS sections so the RP Subcommittee could address the issue in terms of what populations are being studies. This type of information has been difficult to obtain, so there may need to be a recommendation related to grants coding.

The RTDPI Subcommittee felt that the IBCERCC has done a better job of pulling together information about exposure and age of puberty than the IOM report has done. Ysabel said she

was excited about the focus on puberty and overweight, and their references in this section to Latinas and African Americans, but she felt there was not enough information to help communities identify what they can do about this topic. Jeanne suggested that any narrative that Ysabel could prepare would be helpful to pass along.

Connie Engel noted a reference in the RP sections about a CDC program to decrease disparities related to mammography. It might be worth asking RTDPI members to look over some information about this program.

Policy Update

Immediately prior to the RTDPI conference call, Shelia emailed some notes regarding why policy issues should be included in the IBCERCC report, which could potentially be used in an introduction to the policy section. This was in response to Kathy's request to provide this information to explain why certain topics are being covered in the report and how it relates to the legislation that created the IBCERCC. Marcus Plescia stated that when you talk about research, it is important to talk about how research is translated and disseminated in order for it to get used. This was considered by those on the call to be a key point. One example Jeanne mentioned was the Consistency, Accuracy, Responsibility and Excellence in Medical Imaging and Radiation Therapy (CARE) bill which involves training of radiation technicians to make sure they give patients correct doses, etc.

Shelia has several updates she wants to make to the Policy chapter and she will also look at some of the sections of the IOM report as another reference to potentially include. Jeanne said that in terms of regulation, the IOM report refers to the FDA and TSCA. Each Federal agency has different responsibilities and it might be helpful to include a graphic in the IBCERCC report to help demonstrate the "interagency" aspects and how it is difficult to separate research from clinical practice, regulation, and monitoring. A few of the other Subcommittee members liked this idea.

Research Translation, Dissemination, and Communication Update

Liam O'Fallon provided positive feedback on this section.

Kathy suggested that a combined timeline might be included in an introduction to this section, but there was some clarification requested about other timelines that have been mentioned previously. Jeanne requested more information about other IBCERCC plans regarding timelines. Jennifer said the other Subcommittees are not comfortable putting specific timelines on certain areas/topics/studies. Karen Miller recommended that a range of years be provided.

Beverly requested some clarification regarding the desired theme of the timeline and recommended it be titled to help convey the theme, e.g. "progress." There was discussion whether the timeline should include scientific advances, policies/regulation, advocacy and whether it should be focused specifically on breast cancer and the environment, or more broadly

on breast cancer. The answers to these questions will impact what should be contained in a timeline.

Jeanne clarified that the original intent was to show how advocate involvement helped generate interest in breast cancer and the environment, starting from a point in time when the words "breast cancer" were not even said out loud. Ysabel recommended keeping the focus specifically on breast cancer and the environment to highlight what is known or not known. If a timeline is too generic, the message will be diluted. Beverly thought the timeline should be broader in scope than just focusing on advocate involvement in progress related to breast cancer and environment issues. Shelia agreed with Ysabel that if we want to make strong points, the timeline should be slim. For example, could focus on key studies advocates helped launch that helps portray the progress that has been made and highlight information that has not yet been translated. Shelia noted that some studies would never have been launched if it were not for advocates. Jeanne said the current version of the timeline does not yet tell a story. Shelia recommended that the full IBCERCC membership needs to think about the timeline.

Jeanne recommended the RTDPI members identify the key things the Subcommittee wants to highlight, maybe as three or four questions. What has been the role of advocates in advancing X (insert topic)? What was the impact? There may not be direct relationships. It is difficult to determine the best way to narrate this story and we cannot talk about every single milestone. Ysabel suggested maybe there could be a side story instead because it is hard to articulate these points in a timeline format. Stories are more likely to be read than the full report. Jeanne suggested the RTDPI Subcommittee propose a series of stories that involve a variety of people to discuss how they have been involved in the topic of breast cancer and the environment and whether their concerns are being addressed. Karen liked the idea of using the stories to illustrate the interplay between science, policy, and advocacy. Stories could focus on "power of..." (insert themes like "community" (both individual and collective), "science," "policy," "collaboration," and "innovation."

The RTDPI members discussed some of the key questions that everyone involved in the storytelling might need to be asked:

- -What are the gaps on an issue? How did they get filled?
- -What is your vision around this issue?

Jennifer Collins will work with Ed Kang at NIEHS to draft an email that IBCERCC members could send to individuals and invite them to share their stories. NIH does not want multiple IBCERCC members to contact the same people so Jennifer suggested a spreadsheet to keep track of the individuals to be contacted and by whom and she can provide updates. Kathy said if stories could be developed before the end of the year, that would be ideal from SCG's perspective.

Action Items, assignments, and due dates:

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- Feedback requested by RTDPI members on draft report sections by 12/16 or 12/19 to Jeanne. Jeanne and Connie will compile all RTDPI feedback and submit to Kathy by 12/21.
- Jennifer Collins will ask Gwen Collman and Debbie Winn whether the IBCERCC conference call originally scheduled for 12/14 will be rescheduled or if time will be set aside during the January in-person meeting to discuss the IOM report.
- The RTDPI Subcommittee will meet again via conference call on January 10, 2012 at 3 p.m. Eastern.

CERTIFICATION

I hereby certify that, to the best of my knowledge, the foregoing minutes and attachments are accurate and complete.

/Jeanne Rizzo/

Jeanne Rizzo, RN

Chairperson

Research Translation, Dissemination, and Policy Implications Subcommittee Interagency Breast Cancer & Environmental Research Coordinating Committee

/Gwen W. Collman/

Gwen W. Collman, PhD

Executive Secretary

Research Process Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

Proper signatures

Treat as signed, $\S 1.4(d)(2)$